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Reporting Newborn Audiologic Results to State EHDI Programs

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Abstract

Objectives—All US states and territories have an Early Hearing Detection and Intervention (EHDI) program to facilitate early hearing evaluation and intervention for infants who are deaf or hard of hearing. To ensure efficient coordination of care, the state EHDI programs rely heavily on audiologists' prompt reporting of a newborn's hearing status. Several states have regulations requiring mandatory reporting of a newborn's hearing status. This is an important public health responsibility of pediatric audiologists. Reasons for failing to report vary.

Design—The Early Hearing Detection and Intervention-Pediatric Audiology Links to Services (EHDI) facility survey was used to inform reporting compliance of audiology facilities throughout the United States. The survey was disseminated via articles, newsletters, and call-to-action notices to audiologists.

Results—Among 1024 facilities surveyed, 88 (8.6%) reported that they did not report newborn's hearing findings to their state EHDI program. Not knowing how to report to the state EHDI program was the most frequently chosen reason (60%). However, among the 936 facilities that were compliant with the reporting requirements, 51 estimated that they reported less than two-third of all hearing evaluation results (5.4%). Some facilities did not report a normal-hearing result and some failed to report because they assumed another facility would report the hearing results.

Conclusions—Survey results indicated that audiologists were compliant reporting hearing results to the state EHDI programs. However, there is room for improvement. Regular provider

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outreach and training by the state EHDI program is necessary to ensure those who are not reporting will comply and to clarify reporting requirements for those who are already compliant.

Keywords

Audiology facilities; Early Hearing Detection and Intervention; Guidance; Reporting results; State EHDI programs; Survey

INTRODUCTION

All US states and territories have Early Hearing Detection and Intervention (EHDI) programs to monitor and coordinate follow-up services for infants who have not passed their newborn hearing screen (Williams et al. 2015). In addition, 46 states, Guam, and the District of Columbia have passed statutes or regulatory guidance related to early identification of deaf and hard of hearing infants. The “1-3-6” goals have been adopted by all EHDI programs, and are defined as: (1) screening all infants for hearing loss no later than 1 month of age, (2) ensuring that those who did not pass the hearing screen receive an audiologic evaluation no later than 3 months of age, and (3) enrolling those identified with hearing loss in early intervention services no later than 6 months of age. Nationwide EHDI data is available from the Centers for Disease Control and Prevention (CDC). According to the CDC Hearing Screening and Follow-up Survey (HSFS), 97.9% of newborn infants were screened for hearing loss before hospital discharge in 2014. Among those who did not pass the hearing screen, 34.4% of these infants either did not receive the needed hearing tests (loss to follow-up, LTF) or the state/territorial EHDI programs did not receive documentation of a hearing result (loss to documentation, LTD). The 34.4% rate is the national aggregate of states and territories that responded to the 2014 HSFS. The combined LTF + LTD rate across the states ranged from as low as 3.1% to as high as 90.8%, which remains an area of critical concern for states and the CDC. See Table 1 for the LTF/LTD range by states.

Not all states and territories contributed annual newborn hearing screening and follow-up results to the CDC. The number of states and territories that contributed data to the CDC HSFS ranged from 44 to 56 from 2005 to 2014. CDC provided an operational definition for LTF and LTD. LTF was defined as a newborn not receiving needed hearing evaluation. If a newborn received a hearing evaluation but the result was not reported to the state EHDI program, it would be considered as LTD. An example of LTD: the state was notified by an early intervention service provider that a child was enrolled in early intervention for hearing loss, but there was no report of a hearing loss result from the audiologist. The success and effectiveness of EHDI as a public health tracking and surveillance program is dependent upon (1) referral of all infants requiring follow-up to the appropriate facility; (2) clear communication to all follow-up service providers what type of result and follow-up information should be reported to the EHDI program; and (3) providers reporting all infants that have received follow-up service to the state EHDI program.

Forty-two states have passed legislation mandating that service providers report the hearing status of infants to the state EHDI program. The legislation of these 42 states are available

on the National Center for Hearing Assessment and Management (NCHAM) website (www.infanthearing.org, Enacted Universal Newborn Hearing Screening legislation and State EHDI/ UNHS Mandates: Summaries 2011) or on the American Academy of Pediatrics website (https://www.aap.org/en-us/Documents/pehdic_ehdi_%20state_requirements.pdf, State Early Hearing Detection and Intervention Laws and Regulations 2014). New Hampshire EHDI legislation is available at http://www.gencourt.state.nh.us/rules/state_agencies/he-p3000.html. Out of the 42 states, 23 states (54.8%) include broad or direct language requiring providers to report the identification of a hearing loss or the result of a hearing test. For example, the Arizona legislative language is broad: 36–694.C: "When a hearing test is performed on a newborn, the initial hearing test results and any subsequent hearing test results must be reported to the department of health services as prescribed by department rules." In contrast, the Iowa legislative language is direct, clear, and concise 641–3.10 (135):

"The audiologist shall report all of the following information to the department relating to a newborn's or infant's hearing, follow-up, diagnostic audiological assessment, and intervention services, as applicable:

a. The name, address, and telephone number, if available, of the mother of the newborn or infant

b. The results of the hearing screening and any rescreenings, including the diagnostic audiological assessment procedures used

c. The nature of any follow-up or other intervention services provided to the newborn or infant

d. Any known risk indicators for hearing loss"

This survey was undertaken to ascertain if the audiology community was compliant in reporting hearing results to the state EHDI programs and to identify barriers to reporting.

MATERIALS AND METHODS

The type of hearing results audiologists reported to their state EHDI programs, and how often, was extrapolated from the Early Hearing Detection and Intervention-Pediatric Audiology Links to Services (EHDI-PALS.org) facility survey. The EHDI-PALS is a national directory of facilities able to provide audiologic services for newborns through 3 years of age. EHDI-PALS is also a website filled with information, resources, and services for parents with deaf or hard of hearing children. To systematically capture audiology facilities throughout the United States into a directory, a facility survey was designed by a committee of experts in the field of pediatric audiology care from American Speech-Language-Hearing Association, the American Academy of Audiology, NCHAM, the state EHDI programs, and the CDC. The purpose of the survey was to quantify pediatric audiology resource distribution in the United States. A section of the survey asked respondents if they reported hearing results and follow-up information to their state EHDI programs, how frequently they reported, the type of hearing results reported, and if they have not reported the hearing results to the state, the reason for not reporting (see Appendix

A in Supplemental Digital Content 1, http://links.lww.com/EANDH/A341). Facilities equipped to provide audiology follow-up services for newborns through age three were the target of the survey.

The initial version of the survey was tested by six audiologists who came from a variety of clinical settings, including hospitals, universities, private practices, schools, and nonprofit facilities. After revision, 203 audiologists recruited by seven state EHDI Coordinators tested the revised survey. A single audiologist completed the survey on behalf of each facility. American Speech-Language-Hearing Association, American Academy of Audiology, and NCHAM began disseminating the final version of the survey to approximately 5000 audiologists in October 2012 through organizational newsletters and call-to-action notices that were sent to all members via email.

RESULTS

After 3 years of data collection, 1176 facilities completed the EHDI-PALS facility survey. Duplicate and incomplete surveys were excluded which left 1024 (N) facilities in the final sample for analysis. The survey successfully captured audiology facilities from almost every state except West Virginia, Rhode Island, and the District of Columbia.

Facilities Not Compliant With Reporting

Among the 1024 facilities surveyed, 88 (8.6%) facilities reported that they did not report pediatric hearing results to their state EHDI programs, while 936 (91.4%) complied with the state requirement. See Figure 1 for the noncompliant facilities distribution across the United States.

Not knowing how to report to the state EHDI program was the most frequently chosen reason (60%) why the facility did not report hearing results to the EHDI program. Thirteen (14.8%) facilities stated that they had decided not to report, and another 13 stated that they were not familiar with the EHDI program. The remaining 9 (10.2%) did not offer any explanation for not reporting. See Table 2 for types of facilities and proportion of facilities not compliant.

The highest noncompliance rate was reported by audiologists from private practice settings (39.5%) followed by audiologists from school settings (26.1%). Audiologists from hospital settings were the most compliant in reporting the hearing results to the state EHDI programs. Of the 335 respondents from hospital settings, only 1 provider indicated not reporting hearing results to the state EHDI program.

Facilities Compliant With Reporting

Even among the 936 providers who were compliant with reporting, not all the hearing evaluation results were reported to the state EHDI programs. Fifty-one (5.4%) providers estimated that they reported less than two-thirds of all the pediatric hearing loss cases identified. Reasons offered by the respondents varied. Some providers had the impression that it was not necessary to report certain hearing results (21.6%). Some audiologists stated that they assumed other agencies or clinics were responsible for reporting (19.6%) the

hearing evaluation results. The following comment illustrated a typical assumption: “Typically will have second opinion completed at the Children’s Hospital” so “hospital will report.” Some audiologists provided audiologic services infrequently to newborns so they commented that they might not remember to report all cases (17.6%). Others stated that a process barrier prevented them from reporting the results more often. The following comments illustrated these process barriers: “reporting process complicated,” “we were determined” by the EHDI program “as a low volume” clinic for the “number of newborns diagnosed with hearing loss; so we are not” given “online” access “for state reporting” (Fig. 2).

Certain hearing evaluation results were not reported to the state EHDI program. This was a factor contributing to the LTF/ LTD rate. In Table 3, 800 audiologists reported normal-hearing results to the state EHDI program, while 136 audiologists (14.5%) commented that they did not report normal-hearing results. The following comments extracted from the survey illustrated this common impression of the audiologists: “Not needed if normal hearing or temporary conductive loss.” “Children not hearing impaired was not reported.” Among those audiologists who have reported a suspected normal hearing, a suspected hearing loss, or an incomplete test results to the state EHDI program, 74 (0.1%) indicated that they did not sent an updated report when a final definitive hearing result was available.

DISCUSSION

Survey results indicated that an overwhelming majority of audiologists were compliant in reporting pediatric hearing results and follow-up information to their state EHDI programs (91.4%), suggesting a high degree of familiarity with the state tracking and surveillance effort. Audiologists working in hospital settings had the highest compliance rate. Among those facilities not reporting findings to the state EHDI programs, the majority were audiologists from private practices, followed by audiologists in school settings.

According to the 2014 CDC HSFS, the LTF/LTD rate ranged from 3.1% in Kansas to as high as 90.8% in New York. In Figure 1, New York also had the highest number of providers not compliant with reporting the hearing evaluation results to the state EHDI program (19.3%). The most frequent reason indicated by survey respondents from New York was “we do not know how to report to our EHDI program.” This suggested that although some audiologists from New York were not reporting the hearing evaluation result, many audiologists were familiar with their state tracking and surveillance effort. The New York State Codes Rules and Regulations Part 69, Testing for Phenylketonuria and other Diseases and Conditions, Early Intervention Program, and Newborn Hearing Screening specifies that only aggregated hearing screening data must be reported to the state. For those New York audiologists who were reporting, they have been doing so voluntarily. Providing widespread training for audiologists in New York could potentially improve the high LTF/LTD rate.

Improving the clarity of reporting requirements could reduce the overall national LTF/LTD. Twenty-three states have rules and regulations (54.8%) that specify reporting hearing follow-up. For example, the Arizona legislative language is clear in 36–694.C: “When a hearing test is performed on a newborn, the initial hearing test results and any subsequent hearing test

results must be reported to the department of health services as prescribed by department rules." This suggests that all subsequent hearing test results should be reported to the state. According to the 2014 CDC annual survey, Arizona LTF/LTD rate was 34.8%. There were 35 respondents from Arizona captured by the EHDI-PALS survey. All indicated full compliance with the public health rule. However, seven providers did not report a normal-hearing result, 15 did not report an incomplete hearing result, and 4 providers did not send an update to the state when there was a definitive result later. For details see Table 4. More explicit guidance to providers on what should be reported to the state EHDI program is an opportunity for improvement.

Limitations

The EHDI-PALS survey is a facility-based survey and a single audiologist or designated staff member representing the opinion and knowledge of all audiologists working in the same facility completes the survey. Although some state EHDI programs provide training to audiologists on how to report the hearing evaluation results, it is unknown if all audiologists understood or interpreted the reporting requirements the same way. Another limitation was the potential lack of representativeness of the survey. The survey is voluntary and was disseminated through professional organizations and outreach. It was possible that not all facilities that provide audiologic services to newborns and young children completed the survey. Due to the above limitations, only broad-based conclusions can be drawn.

CONCLUSION

Based on findings from this voluntary survey, audiology facilities were overwhelmingly compliant in reporting hearing results to the EHDI programs. The most commonly cited reason why a facility did not report hearing results to the state EHDI program was a lack of understanding on how to report. For those facilities that did report, some facilities were under the impression that certain hearing results, such as normal hearing, did not need to be reported. In addition, when a family goes to another facility for a second opinion, there is a risk of underreporting because audiologists might assume the other facility will report the hearing result. Using this same scenario, when a child is seen for a second opinion in a state where only aggregate data is reported, a child could be reported twice.

To improve documentation and to reduce LTD regular outreach and training is necessary. Clear communication and explicit guidance to the audiology community about who, what, when, and how to report the hearing results should be considered when designing the training curriculum.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

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article are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

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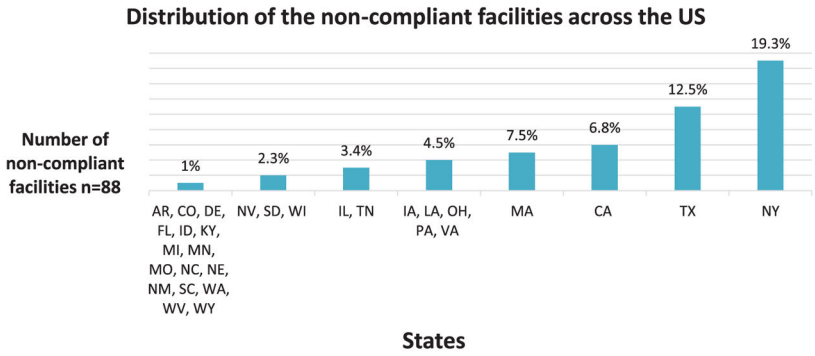

Fig. 1.
Distribution of the noncompliant facilities across the United States.

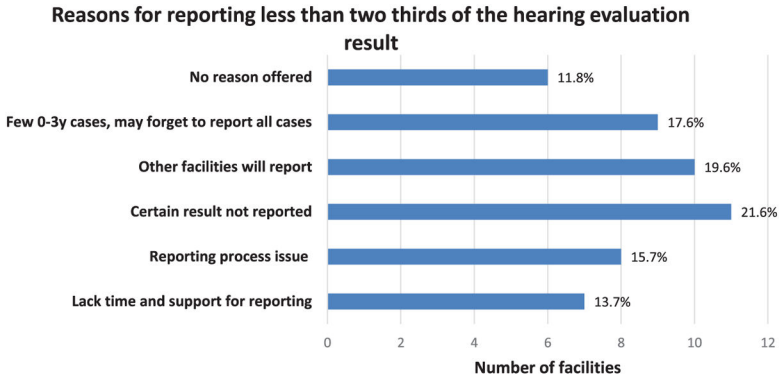

Fig. 2.

Reasons for reporting less than two-thirds of the hearing evaluation result (n = 51).

TABLE 1

Combined Loss to Follow-Up and Loss to Documentation* Rate of States and Territories That Submitted Hearing Screening and Follow-Up Data to the Centers for Disease Control and Prevention in 2014

≤10%	California, Kansas, Massachusetts, Mississippi, Nebraska, Northern Mariana Islands, Palau, Pennsylvania, Vermont, Wyoming
10.1–20%	American Samoa, Connecticut, Hawaii, Indiana, Kentucky, Maine, Maryland, Minnesota, New Jersey, Oregon, Utah, Wisconsin
20.1–30%	Alaska, Georgia, Guam, Idaho, Louisiana, Missouri, New Hampshire, New Mexico, North Carolina, Ohio, Oklahoma, Rhode Island, Tennessee
30.1–40%	Alabama, Arizona, Florida, Idaho, Iowa, Michigan, Nevada
40.1–50%	Marshall Islands, Washington, West Virginia
>50%	Arkansas, Colorado, Delaware, District of Columbia, Illinois, Montana, New York, North Dakota, South Carolina, South Dakota, Texas

* Operational definition for Loss to follow-up and loss to documentation adopted by most states:
Loss to follow-up, a newborn not receiving needed hearing follow-up; loss to documentation, newborn has received a hearing evaluation but the result was not reported to the state Early Hearing Detection and Intervention program.

TABLE 2

Types and proportion of facilities not compliant

Facility Type	Total Number of Facilities N = 1024	Number of Noncompliant Facilities n = 88
Audiology service within a hospital setting	335 (32.7%)	1 (1.1%)
Audiology service within a medical office (eg, ear, nose, and throat medical practice)	204 (19.9%)	15 (17%)
Private practice audiology office	231 (22.6%)	35 (39.5%)
Audiology clinic in a university	60 (5.9%)	4 (4.5%)
Not-for-profit speech and hearing facility	90 (8.8%)	6 (6.8%)
Audiology service within a school	75 (7.3%)	23 (26.1%)
Audiology service within an early childhood center	23 (2.2%)	4 (4.5%)
Audiology service within a military facility	2 (0.2%)	0
Audiology service within the Native American Indian Health System	4 (0.4%)	0

TABLE 3

Types of hearing result reported to the state EHDI programs

Types of Hearing Result Reported	Number of Facilities Reporting to the EHDI Program n = 936
Report only cases referred to us by the EHDI program	30 (3.2%)
Transient hearing loss	660 (70.5%)
Normal hearing	800 (85.5%)
Suspected normal hearing *	596 (63.7%)
Confirmed hearing loss	863 (92.2%)
Suspected hearing loss *	750 (80.1%)
Incomplete test results *	640 (68.4%)
Update of a change in the hearing result	786 (84%)
Hearing aid fitting	483 (51.6%)

* Among those providers who have reported a suspected hearing loss, an incomplete test result or both, 74 providers indicated that they have not sent an update when a definitive hearing result was later obtained.

EHDI, early hearing detection and intervention.

TABLE 4

Arizona respondents

Total number of respondents	35
Number of respondents reported hearing evaluation results to the state early hearing detection and intervention program	35 (100%)
Not reporting transient hearing loss	17 (48.6%)
Not reporting normal-hearing result	7 (20%)
Not reporting suspected normal hearing	17 (48.6%)
Not reporting suspected hearing loss	10 (28.6%)
Not reporting incomplete evaluation result	15 (42.9%)
Did not send update when there was definitive result	4 (11.4%)